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IDENTIFICATION OF NEEDS IN TREATMENT
OF BREAST CANCER

by

LuANN S. MASSEY

A Thesis
Submitted in Partial Fulfillment of the Requirements
for the Degree of Master of Science in Nursing
in the Division of Nursing
Mississippi University for Women

COLUMBUS, MISSISSIPPI

August 1999

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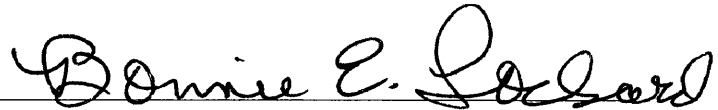
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Identification of Needs in Treatment
of Breast Cancer

by

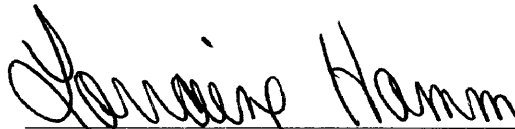
LuAnn S. Massey



Professor of Nursing
Director of Thesis



Assistant Professor of Nursing
Member of Committee



Instructor in Nursing
Member of Committee



Director of the Graduate School

Abstract

Breast cancer has been documented as the second leading cause of death in American women. Many needs are realized during the phases of treatment for breast cancer: at the time of diagnosis, during treatment, and after treatment. The purpose of this descriptive exploratory study was to identify the needs of women with breast cancer during phases of treatment. With the Neuman Systems Model as a theoretical framework, the research question was as follows: What are the needs of women with breast cancer during the phases of treatment? Data were obtained using the Massey Subject Profile and the Massey Questionnaire. The setting of this study was a cancer support center in the Southeastern United States. A convenience sample of 12 women with the diagnosis of breast cancer at least a year prior to data collection was utilized. Data were analyzed using frequency distributions, percentages, and content analysis. Findings revealed information related to aspects of breast cancer would have been most helpful during all phases of treatment. Support was the action that would

have been most helpful and also was the greatest need during all phases of treatment. Concern for children was the greatest concern at the time of diagnosis and during treatment. After treatment, the greatest concern was cancer recurrence or metastasis. Support would have brought the most comfort during all phases of treatment. Recommendations included further research into the effect of alternative therapies and support groups on breast cancer prognosis and the impact of breast cancer on the family.

Dedication

To all the Warrior Women,
Who fight breast cancer valiantly on a
daily basis like true warriors.

Thank you for all of your contributions to this
study.

Acknowledgments

Several people have helped me throughout this past year. Their support and guidance have been invaluable. I would like to express my sincere appreciation and gratitude to them.

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Table of Contents

	Page
Abstract	iii
Dedication	v
Acknowledgments	vi
List of Tables	x
Chapter	
I. The Research Problem	1
Establishment of the Problem	2
Significance to Nursing	10
Theoretical Framework	11
Assumptions	14
Purpose of the Study	14
Statement of the Problem	15
Research Question	15
Definition of Terms	15
II. Review of the Literature	17
III. The Method	55
Design of the Study	55
Variables	55
Setting, Population, and Sample	56
Methods of Data Collection	57
Instrumentation	57
Procedures	58
Methods of Data Analysis	59
Limitations	59

IV. The Findings	60
Description of the Sample	60
Results of Data Analysis	64
V. The Outcomes	79
Summary of Findings	80
Discussion	84
Conclusions	92
Implications for Nursing	94
Recommendations for Further Studies	96
References	98
Appendix	
A. Massey Subject Profile	101
B. Massey Questionnaire	105
C. Approval of Mississippi University for Women's Committee on Use of Human Subjects in Experimentation	110
D. Consent of Director to Conduct Study	112
E. Informed Consent	114

List of Tables

Table	Page
1. Subject Data Concerning Tumor Stage and Medical Treatment of the Massey Subject Profile Using Frequencies and Percentages	62
2. Responses of Self-Education of Breast Cancer on the Massey Subject Profile Expressed in Frequencies and Percentages . . .	64
3. Theme Frequency and Percentage Response to Most Helpful Information During Treatment Phases for Breast Cancer on the Massey Questionnaire	66
4. Theme Frequency and Percentage Responses to Most Helpful Action Taken by Self or Others During Treatment Phases for Breast Cancer on the Massey Questionnaire	68
5. Frequency and Percentage Response to Greatest Need at the Time of Diagnosis of Breast Cancer on the Massey Questionnaire	70
6. Frequency and Percentage Responses to Greatest Need During Treatment for Breast Cancer on the Massey Questionnaire . .	71
7. Frequency and Percentage Response to Greatest Need After Treatment for Breast Cancer on the Massey Questionnaire	72

8. Frequency and Percentage Response to Greatest Concern at the Time of Diagnosis of Breast Cancer on the Massey Questionnaire	74
9. Frequency and Percentage Response to Greatest Concern During Treatment for Breast Cancer on the Massey Questionnaire	75
10. Frequency and Percentage Response to Greatest Concern After Treatment for Breast Cancer on the Massey Questionnaire	76
11. Theme Frequency and Percentage Response to What Brought Most Comfort During Phases of Treatment for Breast Cancer on the Massey Questionnaire	77

Chapter I

The Research Problem

Breast cancer is the second most common cause of death from cancer in American women. Excluding nonmelanoma skin cancer, breast cancer is the most common malignancy among women. This year there will be an estimated 186,000 new cases of breast cancer diagnosed and 46,000 women will die of breast cancer (Bines & Gradishar, 1997). Following the diagnosis of breast cancer, frequently some form of treatment will usually be recommended. Such treatment may involve surgery and any one of the following adjuvant therapies, alone or in combination: radiation therapy, chemotherapy, ovarian ablation, and Tamoxifen administration. The diagnosis of breast cancer and the treatment that follows are highly threatening experiences for women. The women with breast cancer must deal with not only the physical impact of treatment regimens, but also the emotional aspects of a life-threatening illness (Galloway et al., 1997).

The threat to life posed by breast cancer is real. Therefore, the diagnosis of breast cancer elicits many fears and concerns in women. Fears and concerns can continue throughout, and following completion of any breast cancer treatment and the adjustment to the diagnosis and treatment of breast cancer occurs over a period of time (Hoskins, 1997). Many different needs relating to all aspects of life for the women affected are realized during the diagnosis, treatment, and the years following treatment of breast cancer. The purpose of this study was to identify needs of women with breast cancer during the various phases of treatment: the time of diagnosis, during treatment, and the years following treatment of breast cancer.

Establishment of the Problem

Breast cancer is the most commonly diagnosed cancer in women in the United States ("Guide to Clinical and Preventive Services," 1996). Over 180,000 new cases of invasive breast cancer were diagnosed in 1997, according to the American Cancer Society. The recommended treatment for the majority of these cases involved either a total mastectomy or some type of breast-conserving surgery. The

primary breast-conserving surgery was usually followed by radiation therapy. Reconstruction may or may not have followed a total mastectomy. Chemotherapy may have been administered in both incidences (Hoskins, 1997). Other forms of medical treatment for breast cancer, often referred to as adjuvant therapy, include ovarian ablation, Tamoxifen, and chemotherapy (Ravdin, 1995).

Physical and emotional side effects following adjuvant therapy and side effects of surgery were frequent in breast cancer treatment and all required management. Accurate monitoring of side effects was an important part of controlling adverse physical and psychological responses to treatment (Hoskins, 1997). Important long-term physical side effects that have occurred after systemic adjuvant therapy for breast cancer include premature ovarian failure, secondary malignancies, and cardiovascular toxicity. These complications are often irreversible. These complications also occur in women who have been cured of breast cancer (Bines & Gradishar, 1997). Other physical side effects that have occurred with breast cancer treatment include nausea, vomiting, hair loss, fatigue, skin changes, lymph edema, menopausal symptoms, weight gain, and fertility and reproductive

changes. These side effects frequently have an enormous impact on the physical well-being and overall quality of life for the women affected. The impact of initial diagnosis and treatment on physical well-being continued into long-term survivorship for the majority of women (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Interestingly, women frequently have reported heightened anxiety toward the end of breast cancer treatment, indicating that the cancer treatment had made them feel that their cancer was under control (Keller, 1998).

Psychological impact of breast cancer in women includes depression, anxiety, uncertainty about the future, appearance and self-concept, fear of a second or recurrent cancer and metastasis, and distress from surgery (Ferrell et al., 1998). An awareness and preoccupation with the possibility of death often occur in women with breast cancer. These women often struggle with trying to maintain their sense of hopefulness while at the same time balancing the ever-present reality that breast cancer could recur. Even women who currently had no active disease or who were long-term survivors believed that their lives had been shortened by the effects of breast cancer and treatment, and thus would not live long lives

(Ferrell et al., 1998). Psychological distress often differs depending on the type of adjuvant therapy utilized and the degree of cancer involvement. In a study conducted over a one-year period after diagnosis of cancer, Hoskins (1997) found that women undergoing chemotherapy reported more psychological distress and a lower health status than those who were not receiving chemotherapy. Also, women with axillary lymph nodes positive for cancer cells consistently perceived their health as lower than those women with axillary lymph nodes negative for cancer cells. However, psychological distress and perceived health status improved over the one-year time for all of the women in the study.

Women with breast cancer have described the importance of spiritual support and spirituality in assisting them in facing breast cancer. However, this is often overlooked in the literature, even though many women report how spirituality enabled them to find meaning in their lives despite the life-threatening illness of breast cancer (Ferrell et al., 1998).

Ferrell et al. (1998) found that breast cancer had a tremendous effect on social functions at home and in the work setting. Women often described the impact of illness

and treatment on maintaining employment. However, the women also reported the significant effect that returning to work had on their coping with the cancer diagnosis and on their ability to maintain a sense of normalcy. Women also related concerns regarding the financial impact of cancer and treatment.

Ferrell et al. (1998) also found that one of the greatest areas of social concern in women with breast cancer was related to the impact of breast cancer on the family. Women were intensely concerned with the fear of breast cancer occurring in their daughters. This particular concern was often revealed as a greater concern to the women than their own health. Women with breast cancer who have small children are often concerned about whether they will live long enough to see their children grow up and the impact breast cancer may have on their children's lives and well-being.

Breast cancer also has a tremendous effect on the spouses of these women. Spouses often experience as much distress from breast cancer as the client. The spouses suffer from anxiety, threat of losing their mate, and seeing their mate suffer (Keller, 1998). The effects of breast cancer treatment frequently have an effect on the

sexual relationship between the woman and her spouse. Women described the loss of the breast as well as menopausal symptoms associated with breast cancer as often having a negative effect on their sexual relationship (Ferrell et al., 1998). Women with breast cancer often reported their sense of femininity and body image were deeply affected by breast cancer. These effects were compounded in younger women (Keller, 1998).

Another important issue regarding young women with breast cancer is the effects of breast cancer treatment on fertility and childbearing. Ovarian failure often occurs after chemotherapy treatment. Of the newly diagnosed breast cancers, 10 to 20% will occur in women of childbearing age. A large majority of these women will undergo chemotherapy treatment. Fertility after breast cancer treatment is a great concern in young women. The common practice is to recommend a waiting period of 1 to 2 years after the completion of breast cancer treatment before conceiving. This is due to the higher relapse risk during the first 2 years after treatment. However, based on age and the risk of chemotherapy related amenorrhea, the longer the waiting period, the less likely a woman

will be able to conceive (Bines & Gradishar, 1997), which presents a great dilemma for young women.

Survival rates differ in women with breast cancer according to the breast cancer tumor stage, grade, axillary lymph node involvement, and type of adjuvant therapy utilized. Bines and Gradishar (1997) stated a recent overview of randomized adjuvant treatment trials in early stage breast cancer showed approximately a 30% reduction in the recurrence rate of breast cancer and an approximate 20% improvement in survival. Younger women benefitted greater from adjuvant chemotherapy, whereas women older than 50 years showed a greater survival rate with the administration of Tamoxifen 2 to 5 years after local therapy.

Ferrell et al. (1998) noted that women with breast cancer frequently reported extreme fears associated with the possibility of recurrence and that the fear of death appeared to be heightened in breast cancer survivors. The researchers further asserted that women often described their continual struggle for a sense of normalcy, even though their physical activities had resumed and the majority of their lives were similar to their daily lives before diagnosis. Additionally, breast cancer survivors

described how dramatically cancer had altered their lives in terms of life priorities and life meaning.

Many fears, concerns, and needs are realized during the diagnosis, treatment, and the years following treatment for breast cancer. Much of the research conducted thus far has concentrated on the early diagnosis and treatment issues, concentrating mainly on the physical aspects. The majority of the existing research concerning the effects of breast cancer on the psychological aspects of women has been concerned with the initial diagnosis and early treatment phases. The effects of breast cancer on the social, and especially the spiritual, aspects of women have been greatly ignored in the research. Breast cancer impacts all areas of a woman's life. Continual assessment of areas of distress is important in the care of women with breast cancer. The purpose of this study was to obtain and identify information regarding the needs of women with breast cancer during various phases of treatment: the time of diagnosis, during treatment, and the years following treatment of breast cancer.

Significance to Nursing

Identifying the needs of women with breast cancer during the time of diagnosis, treatment, and the years following treatment is important. With identification of these needs, nurse practitioners and other health care providers can anticipate and address the concerns and needs of the client during treatment phases. By anticipating these needs, information and education, along with resources, can be available to assist the clients concerning these issues. Nurse practitioners and other health care providers can educate the clients on what to expect and can develop management strategies to help the clients coordinate their treatment with routine responsibilities and have maximum control of side effects and symptoms. The identification of needs also will enable health care providers and other persons associated with women with breast cancer to understand more fully what the client is experiencing. This will allow more therapeutic responses and care. Nurse practitioners' and other health care providers' awareness of common reactions to the crisis of cancer may enable them to offer adequate support and possibly identify the clients who are adjusting poorly

and who may be at risk of developing severe emotional distress (Keller, 1998).

Nursing interventions, such as giving information relevant to the client's needs, may help the client with breast cancer to have realistic expectations about her illness and subsequent illness related events. Furthermore, if there is congruence between what is expected and what actually transpires, then interpretation and understanding of the experience of the illness are eased. Providing relevant information to clients undergoing cancer treatment benefits clients in enhancing their ability to care for themselves and increasing their participation in their usual activities (Galloway et al., 1997). Anticipating adverse side effects can enable the client to deal with the side effects and develop adequate coping strategies. Also, when women with breast cancer are informed their reactions and side effects are normal, the women usually experience decreased anxiety (Keller, 1998).

Theoretical Framework

Neuman's (1996) Systems Model was the theoretical framework for which this study was based. Neuman (1996) views the client wholistically as a system consisting of

physiological, psychological, sociocultural, developmental, and spiritual variables. The client system is seen as an open system interacting with the environment. Environment is defined in this model as all of the internal and external factors interacting with the client. The client also has a created environment that moves all the variables of the system toward stability (Neuman, 1996). Breast cancer impacts all aspects of a woman's life. The diagnosis and treatment of breast cancer, as well as the time periods following breast cancer treatment, bring about needs that encompass all of the wholistic realms presented in Neuman's (1996) Systems Model.

According to Neuman (1996), system stability is altered at times by environmental forces known as stressors. Stressors are classified as intrapersonal, interpersonal, and extrapersonal and have been shown to potentially penetrate a client's flexible and normal lines of defense. Breast cancer was viewed as a stressor within this model's framework. According to this model, the client's flexible line of defense protects stressors from breaking through the client's normal line of defense. A client's normal line of defense is a stability state

representing the client's patterns of coping with stressors while functioning within his or her environment. Stressors are defended with resource factors of the client called lines of resistance. When a stressor invades a client's normal line of defense, the resulting amount of system instability is known as the degree of reaction. The degree of reaction of the client to the stressor, breast cancer, is dependent on the client's lines of resistance (Neuman, 1996).

The client is helped to retain, attain, and/or maintain system stability with interventions. The three levels of intervention identified by Neuman are primary, secondary, and tertiary. When a stressor is identified, primary prevention is implemented before illness occurs. Secondary prevention is initiated after the occurrence of stressor symptoms. Treatment of breast cancer fell under secondary prevention in Neuman's (1996) Systems Model. Tertiary prevention follows secondary prevention and focuses on stabilizing the client system. Reconstitution represents the adapted state to all environmental factors relating to all of the system variables. When system needs are met and all of the client's system parts are in harmony, wellness exists. Illness occurs when there are

unmet needs and disharmony of system parts of the client. Perceived needs of the client in this study encompassed fears, concerns, and needs experienced at the time of diagnosis, during treatment, and after treatment of breast cancer. The meeting of the needs of the client fell under tertiary prevention in Neuman's Systems Model and would assist the client in reconstitution and mobilization of the system toward wellness (Neuman, 1996).

Assumptions

For the purpose of this study, the following assumptions were identified:

1. Forms and approaches of breast cancer treatment exist.
2. Women with breast cancer experience needs during phases of breast cancer treatment.
3. Breast cancer is a stressor that impacts a woman's normal coping defense pattern.

Purpose of the Study

The purpose of this study was to identify the needs of women with breast cancer during phases of treatment.

Statement of the Problem

Breast cancer has been documented as the second leading cause of cancer death in American women. Multiple treatments exist for breast cancer. Breast cancer diagnosis and treatment can be anxiety provoking, and women perceived a variety of needs during these times. Identification of needs in women with breast cancer is important in order to enable health care providers to better meet the needs of these clients and provide holistic care.

Research Question

This study was guided by the following research question: What are the needs of women with breast cancer during the phases of treatment?

Definition of Terms

For the purpose of this study, the following definitions were used:

Needs: Theoretical: Needs, as defined in the New Webster's Dictionary (1992), are something required, desirable, wanted, or necessary. Operational: For the purpose of this study, needs were defined by answers on the Massey Questionnaire.

Women with breast cancer: Theoretical: a female diagnosed with carcinoma of the breast. Operational: For the purpose of this study, women with breast cancer were those females diagnosed with primary carcinoma of the breast at least one year prior to data collection who were attending a cancer support center in a southeastern city.

Phases: Theoretical: Phases, as defined in the New Webster's Dictionary (1992), are each of the successive aspects or stages in any course of transition or development. Operational: For the purpose of this study, phases of treatment was defined as the time of diagnosis of breast cancer, the time during treatment of breast cancer, and the time following therapy for breast cancer.

Treatment (of breast cancer): Theoretical: The use of any surgical and/or systemic adjuvant therapy for breast cancer. Operational: For the purpose of this study, treatment of breast cancer was defined by answers on the Massey Subject Profile.

Chapter II

Review of the Literature

A review of literature related to breast cancer revealed a significant amount of research. Though numerous studies relating to treatment of breast cancer exist, there is a scarcity of studies evaluating quality of life and needs beyond the realms of the physical and treatment related issues. There is also a lack of research to determine the needs of women with breast cancer beyond the time frames of diagnosis and treatment.

In 1997, 180,200 new cases of invasive breast cancer were diagnosed according to the American Cancer Society. The recommended treatment for the majority of these cases involved either a total mastectomy or some type of breast-conserving surgery. The primary breast-conserving surgery was usually followed by radiation therapy. Reconstruction may or may not have followed a total mastectomy. Chemotherapy may have been administered in both incidences. Physical and emotional side effects following adjuvant therapy, as well as side effects of surgery, were

frequent in breast cancer treatment and all required management. Accurate monitoring of side effects was an important part of controlling the side effects and adverse psychological responses. Based on these findings, Hoskins (1997) sought to describe variations in side effects of treatment of breast cancer and concurrent variations in psychological distress and perceived health status.

The variables of this study were psychological distress, perceived health status, and side effects of treatment for breast cancer. Psychological distress was defined as dysphoric thoughts and feelings as a result of illness and its sequelae. Perceived health status was defined as perception of health at a given phase of illness.

The researchers used a time series for a period of one year with six collection points. The study was a continuation of a previous research study in 1996 by Hoskins, Budin, and Maislin (cited in Hoskins, 1997). The convenience sample included 93 women who completed all of the medical data sets. The subjects were Caucasian, married, had an average age of 51.4 years, and an average of 14.9 years of education. The inclusion criteria were the following:

1. The patient was diagnosed with breast cancer.

2. The patient had a spouse or male partner who lived with her and agreed to participate.

3. The patient and her partner could read English.

The exclusion criteria were the patient had a previous history of cancer and either the patient or partner had a history of psychiatric hospitalization or drug abuse. The sample was recruited from the practices of breast surgeons in the New York City metropolitan area at three major medical centers. The sample was divided into groups of breast-conserving, mastectomy, and positive and negative nodes. Each group was subdivided into those who received adjuvant therapy and those who did not receive adjuvant therapy. The adjuvant therapy groups included radiation only, chemotherapy only, and radiation and chemotherapy combined.

Instrumentation included three tools:

1. The Psychological Distress Subscale measured the psychological distress.

2. The Multilevel Assessment Inventory measured the perceived health status, which was divided into categories of "no problems" and "better health."

3. The Treatment Recovery Inventory, a checklist of current therapy and side effects, was utilized to document effects of therapy.

The Institutional Review Boards of three medical centers gave their approval for the study. The patients were referred to the study by surgeons according to inclusion criteria. The medical records of each subject were reviewed to ensure eligibility. The subjects signed consent forms and completed demographic forms after agreeing to participate in the study. The four investigators consisted of the principal investigator, an oncology clinical nurse specialist, the director of nursing research at one of the medical centers, and a doctoral student in nursing. Assessments were scheduled at 7 to 10 days, 1 month, 2 months, 3 months, 6 months, and one-year post-surgery. In order to maintain rapport, the initial investigator who made contact with the patient followed the patient throughout the one-year period. A separate set of inventories was mailed to each partner at each data collection time. The partners were not to consult with each other during the completion of the inventory. The inventories were to be completed according

to the respondent's perception since the previous collection time.

Data analysis by the researcher was conducted using frequencies and percentages of women experiencing side effects at the six data collection times to identify patterns. Variances were utilized to assess whether the changes over time differed by type of surgery or node status. Huyhn-Feldt was the statistical test used to calculate the p values for unequal variances and co-variances. In order to reduce a Type I error rate, comparisons were characterized only if significant group-by-time interactions were observed.

Responses to the Psychological Distress Subscale produced a mean of 13.10 and a standard deviation of 4.0. Breast-conserving surgery patients were compared to mastectomy patients. Psychological distress occurred over time with a significance of $p < .0006$. Related to perceived health status, the changes over time were significant at $p < .001$. The adjustment outcomes of patients with radiation, chemotherapy, or no adjuvant therapy were analyzed by one-way variance. The researchers found a pattern of significance (3-month interval,

$p < .05$; 6-month interval, $p < .009$) of psychological distress and perceived health status.

Persistent issues were fatigue and emotional distress. Breast-conserving and mastectomy groups experienced improvement of psychological distress and perceived health status over time with no significant differences between groups. However, patients receiving chemotherapy and patients not receiving chemotherapy experienced significant differences between 3 and 6 months. Women undergoing chemotherapy reported more psychological distress and a lower health status than those who were not receiving chemotherapy. Patients in the positive and negative node groups experienced no significant decline in psychological distress over time. Emotional adjustment and perception of overall health improved over time for both node groups; however, women with positive nodes consistently perceived their health as lower than those with negative nodes. Psychological distress and perceived health status improved over time during the one-year period for all groups.

Hoskins (1997) concluded that adjustment to the diagnosis and treatment of breast cancer occurred over a period of time. Continual assessment of psychological

distress and perceptions of overall health are important in the care of patients with breast cancer.

Hoskins (1997) identified patterns and differences concerning surgical procedures and use of adjuvant therapies for breast cancer. The information obtained in this study was used in the current study to help identify patterns that occur with breast cancer treatment.

Bastert et al. (1998) examined the effect of adjuvant clodronate treatment on metastasis prevention in breast cancer. Bisphosphonates were found to inhibit the activity of osteoclasts and were thereby effective against the increased bone resorption caused by certain diseases. The bisphosphonate clodronate (chlodronic acid) was found to reduce the frequency of skeletal complications in patients who had breast cancer and metastatic bone disease. Animal experiments and preliminary clinical observations indicated early clodronate therapy reduced the incidence of new bony metastases in breast cancer. Based on these findings, Bastert et al. (1998) investigated the effects of clodronate on the incidence and extent of new metastases in patients with breast cancer. The initial statistical projection was that there would be a difference of 10% between the experimental and control

group in the rate of bony metastases after follow-up of 36 months.

The variables were the incidence and number of new bony and visceral metastases and the length of time to their appearance. Standard surgical therapy consisted of either mastectomy or breast-conserving surgery. Adjuvant systemic treatment in this study consisted of CMF (cyclophosphamide, methotrexate, and fluorouracil), EC (epirubicin and cyclophosphamide) or FEC (fluorouracil, epirubicin, and cyclophosphamide), Tamoxifen, Goserelin or chemotherapy, and endocrine therapy which consisted of Tamoxifen plus standard CMF. Regarding tumor staging, T1 denoted tumor ≤ 2 cm in greatest dimension, T2 tumor > 2 cm to 5 cm in greatest dimension, T3 tumor > 5 cm in greatest dimension, and T4 tumor of any size with direct extension to chest wall or skin. In regard to axillary node staging, "N0" denoted no regional lymph node metastasis, N1 metastasis to one or more movable ipsilateral axillary lymph nodes, and N2 metastasis to one or more ipsilateral axillary lymph nodes fixed to another node or to other structures. In regard to estrogen receptor status and progesterone receptor status, positive status was defined as ≤ 20 fmol of protein per milligram,

and negative status as < 20 fmol of protein per milligram. Tumors were graded according to the Scarf-Bloom-Richardson classification where Grade I indicated a well-differentiated tumor, Grade II a moderately well-differentiated tumor, and Grade III a poorly differentiated tumor.

Bastert et al. (1998) used a prospective, randomized, and non-placebo controlled design that was carried out at the University Hospital-Heidelberg between February 1990 and April 1997. One hundred and fifty-seven patients received oral clodronate at a dose of 1600 mg per day for 2 years, and 145 patients received standard follow-up with no clodronate administration. The median length of observation was 36 months. All patients in both groups received standard surgical treatment and customary hormonal treatment or chemotherapy. Inclusion criteria were primary breast cancer that was classified as being at stage T1, T2, T3, or T4 and histologically classified as stage N0, N1, or N2; immunocytochemical detection of at least one tumor cell in a bone marrow aspirate, which indicated a high risk of ensuing metastasis and provision of written informed consent. Randomization was carried out postoperatively subsequent to receipt of results of the

histologic examination, assessment of prognostic factors, and tumor cell immunocytologic studies, but before decisions were made regarding adjuvant systemic treatment. No stratifications were made according to the types of adjuvant treatments.

Bastert et al. (1998) determined that the patients' median age was 51 years, ranging from 24 to 78 years. T2 stage tumors were the most common at 46%, tumors less than 2 cm were at 37%, and T3 or T4 tumors were at 17% in the sample. One hundred and forty-three patients were nodal status negative, and 159 patients had involvement of the axillary lymph nodes. Seventy-three percent of primary tumors tested were estrogen receptor positive, and 63% were progesterone receptor positive. One hundred and thirteen patients were premenopausal, and 189 were postmenopausal. Seventy percent of the primary tumors assessed were Grade I or Grade II, and 30% were Grade III. Eighty-one percent of the sample patients received adjuvant therapy, and no significant differences were found in the proportion of patients receiving adjuvant therapy between the clodronate and the control groups.

Patients assigned to the clodronate group (n = 157) received 1600 mg of oral clodronate per day for 2 years

and were instructed to take 4 capsules (400 mg each) of clodronate every morning at least one hour before breakfast with water only and never with meals containing calcium. Clodronate therapy was continued in all patients with metastatic disease in the clodronate group and was started in control group patients (n = 145) in whom metastasis to bone was identified. Radiation was performed on osteolytic lesions in the event of bone pain or the threat of pathologic fractures. Patients with hypercalcemia received 1500 mg of intravenous clodronate over a period of 2 hours.

All patients had follow-up investigations in the University Women's Hospital according to standard protocol. During the first 2 years the interval between investigations was 3 to 4 months. A history was taken and a physical exam was performed at every visit. Yearly chest radiographs, bone scans, liver ultrasounds, and mammograms were performed. Every 3 months blood counts and measurements of tumor antigens in serum were carried out. Additional x-ray films of affected areas were obtained if there was evidence of metastasis to bone. Patterns of metastasis were identified at the end of the study. Two independent radiologists assessed bone lesions seen on

radiographs. Statistical analysis did not include skeletal complications, but skeletal complications were recorded as events in this study.

The researchers used three tools for statistical analysis. The chi-square test was used to assess differences between the groups in the frequency of individual prognostic factors. Differences in overall and metastasis free survival were investigated with the use of the Kaplan Meier analysis and the log rank test. Probability values were calculated for two-tailed outcomes. Systat software and SAS software were used for the statistical data processing.

Bastert et al. (1998) found distant metastases (bone or visceral) in 21 women in the clodronate group and 42 women in the control group ($p < .001$) during the median observation period of 36 months. The clodronate group had the development of bony metastases in 12 women and the development of visceral metastases in 13 women, compared with bony metastases development in 25 women and visceral metastases development in 27 women in the control group ($p = .003$). Twenty-two patients in the control group died, and 6 patients in the clodronate group died ($p = .001$). The mean number of bony metastases was 3.1 in the

clodronate group and 6.3 in the control group. Significant differences were shown between the two groups in metastasis free survival ($p < .001$) and overall survival ($p = .001$). Significant differences were also found between the groups with regard to the proportion of patients with bony metastases ($p = .003$) and visceral metastases ($p = .003$). The identification of the reduction in nonosseous metastases in the group of women given clodronate was an unexpected finding. Based on these findings, Bastert et al. (1998) concluded that clodronate administration can reduce the incidence and number of new bony and visceral metastases in women with breast cancer who are at high risk for distant metastases.

Bastert et al. (1998) identified numerous adjuvant systemic treatments used in breast cancer. The researchers also discussed the breast cancer classification categories. This information was used in the current study to help identify the various adjuvant systemic treatments used in breast cancer and to classify and categorize breast cancer for statistical purposes.

The long-term outcome of patients with early stage breast carcinoma receiving breast-conserving therapy was examined by Kini et al. (1998). Breast-conserving therapy

(BCT) has been established as an equivalent treatment to mastectomy in regard to local and regional control, disease free survival, and overall survival. Retrospective studies regarding long-term results with BCT have mainly been reported from academic institutions affiliated with medical schools. The role of the hospital setting has been one of the factors evaluated for an association with treatment outcome. Kini et al. (1998) examined outcomes in patients with early breast carcinoma who were treated with BCT in a community hospital setting and sought to determine if rates of control were comparable to those reported from academic institutions. Kini et al. (1998) also sought to determine what clinical, pathologic, and treatment related factors may have influenced an increased rate of local recurrence after BCT.

The main dependent variable studied was the incidence of local recurrence of breast carcinoma. Other dependent variables studied were the incidence of regional and distant metastases, disease free survival, overall survival, and cause specific survival. Clinical and pathologic variables were tumor stage, pathologic tumor size, nodal status, overall pathologic stage, age, and histology. Treatment related variables were tumor margins,

radiation boost, status at reexcision, receipt of chemotherapy, and cumulative radiation dose.

Local recurrence was defined as the detection of cancer in the parenchyma and/or skin of the treated breast occurring before or simultaneously with the discovery of regional failure or distant metastases. Regional recurrence was defined as the reappearance of cancer in the regional lymph nodes before or simultaneously with metastasis. (Kini et al., 1998, p. 128)

Overall survival (OS) in this study reflected all deaths and cause specific survival (CSS) reflected those deaths attributed to breast carcinoma.

Four hundred cases of Stages I and II breast carcinoma managed with BCT at the study institution between January 1980 and December 1987 were used for this retrospective series of study. The sample consisted of 400 carcinomas in 390 women (10 patients presented with bilateral breast carcinoma). Fifty-four years was the median age at diagnosis with a range of 29 to 85 years. Follow-up for patients in this study had a median of 108 months with a range of 1 to 179 months. There were 292 surviving patients with a follow-up median of 118 months with a range of 3 to 180 months.

Patients were staged using the criteria from the 1992 American Joint Committee on Cancer. The criteria

established at the Joint Center for Radiation Therapy, Harvard Medical School, was used to define recurrences. The Kaplan-Meier method was used to estimate actuarial results for local recurrence, regional recurrence, distant metastases, and survival. The two-tailed Mantel-Haenszel log rank test was used to analyze statistical differences between univariate analysis curves. The Cox regression model was used for the multivariate analysis of covariates for local recurrence, OS, DFS, and CSS. Local and regional analyses were performed on the 400 cases of breast carcinoma. The analysis of the rate of distant metastases, DFS, OS, and CSS was performed on all 390 patients. Statistical significance was considered with a p value $\leq .05$. Radiation treatment completion dates were used for calculating all time intervals. SYSTAT version 5.04 and StatXACT-3 version 3.02 were used for statistical analysis.

Kini et al. (1998) found 37 local recurrences in the 400 treated breasts. On univariate analysis, patient's age ≤ 35 years (25% vs. 8%, $p = .004$) and the presence of positive surgical margins (20% vs. 7%, $p = .018$) were associated with an increased rate of local recurrence. Multivariate analysis showed a single significance of age

≤ 35 (RR, 11.05; 95% confidence interval, 2.93 to 41.6).

Nineteen patients experienced regional recurrence, and 67 patients developed distant metastases.

For the entire group, the DFS, OS, and CSS at 5 and 10 years were 83%, 86%, and 89% and 74%, 74%, and 81%, respectively. The DFS, OS, and CSS for Stage I patients were 91%, 94%, and 96%, respectively, at 5 years and 81%, 88%, and 91%, respectively, at 10 years. The DFS, OS, and CSS for Stage II patients were 73%, 76%, and 81%, respectively, at 5 years and 65%, 60%, and 69%, respectively, at 10 years. (Kini et al., 1998, p. 131)

Kini et al. (1998) concluded that patients with early-stage breast carcinoma receiving breast-conserving therapy in a community hospital setting produced comparable results to academic and multi-institution trial reports in contemporary studies. One of the most important factors associated with an increased risk of local recurrence in this study was patient's age ≤ 35 years. This finding was similar to findings from other studies.

Kini et al. (1998) identified many variables possibly associated with local recurrence of breast carcinoma after BCT, as well as the rate of local recurrence following BCT in a community hospital setting. Kini et al. (1998) also examined the long-term results with BCT. This information was used in the current study for evaluation and

identification of prevailing results and possible concerns arising from the various breast cancer treatments.

The purpose of Part I of the study conducted by Ferrell, Grant, Funk, Otis-Green, and Garcia (1998) was to describe the impact of breast cancer on the physical and social well-being domains of breast cancer survivors through qualitative analysis. Ferrell et al. (1998) defined physical well-being as "the control or relief of symptoms and the maintenance of function and independence" (p. 400). Social well-being was defined by Ferrell et al. (1998) as "a way to view not only the cancer or its symptoms, but also the person surrounding the tumor, it is the means by which we recognize people with cancer, their roles, and relationships" (p. 400). Guiding this study were the following questions: "1) What are the individual aspects and domains of QOL for women with breast cancer? and 2) What is the impact of breast cancer and treatment on QOL?" (p. 400).

A convenience sample of 21 subjects at least one year beyond initial diagnosis and at least 3 months beyond the last completed treatment participated in this study. The sample was obtained from the City of Hope National Medical Center (COH) and was derived from record reviews and

physician/nurse referrals. Stratification of the sample represented three age groups: individuals < 40 years of age, individuals aged 40 to 60 years, and individuals > 60 years. The mean age was 50 years, ranging from 22 to 79 years. Fifty-seven percent of the sample were white, 14% were Hispanic, and 19% were black. The highest percent of the sample had a household income > \$40,000. Twenty-seven months was the mean time since treatment. Seventy-six percent of the sample had mastectomies, 24% had lumpectomies, 81% had chemotherapy, 81% had radiation therapy, and 57% had hormonal therapy. The mean time since breast cancer diagnosis was 34.2 months, with a range of 9 to 180 months.

Three tools comprised the instrumentation of this study. A demographic questionnaire included the variables of age, ethnicity, income, treatment type, and time since initial diagnosis and treatment. The Quality of Life Breast Cancer Version (QOL-BC) consisted of 43 items representing the four domains of QOL: psychological well-being (20 items), physical well-being (8 items), social well-being (8 items), and spiritual well-being (7 items). The semi-structured interview guide contained questions designed to obtain contextual information about the

woman's breast cancer in the initial portion and questions addressing QOL domains in the latter portion. Responses were facilitated with follow-up probes.

The participants completed the Demographic Questionnaire and the QOL-BC after giving informed consent. Data using the semi-structured Interview Guide were then collected with individual interviews lasting typically 1 to 3 hours. Interviews were tape-recorded and then transcribed verbatim. The nurse project director conducted the interviews either in the patient's home or in a private area at the institution. Findings were validated or clarified as needed with follow-up telephone calls after initial interview analysis. Invitations to attend one of three focus group sessions to discuss QOL issues with other study participants also were extended to the women.

Qualitative analysis of interview transcripts from this study was reported. Content analysis on each of the transcribed interviews was performed by the principal investigator and one additional member of the research team selected on a rotating basis. Each transcript was read several times to identify recurrent themes. These

initial codings were discussed and revised in a total of 11 team meetings over a one-year period.

Results relating to physical and social well-being in this study were reported. Major themes associated with the problem of pain as an aspect of physical well-being included descriptions of pain occurring during active treatment and pain described as the presenting symptom that led to reporting changes in the breast and consequently to a diagnosis of breast cancer. Pain derived from surgery, radiation, and chemotherapy was also described. Reluctance to report pain for fear of its possible indication of recurrent disease and also reluctance to take pain medications, especially on a long-term basis, were also recurrent themes.

Additional physical symptoms impacting the physical well-being domain of QOL were described. These included fatigue, weight gain, menopausal symptoms, fertility, vaginitis, nausea, and hearing loss.

Regarding social well-being, Ferrell et al. (1998) found that breast cancer had a tremendous impact on social and role function not only at home, but also in the work setting. Women described the impact of breast cancer illness and treatment on their ability to maintain

employment. The women also emphasized the effect that returning to work had on their coping with the breast cancer diagnosis and maintaining a sense of normalcy. Many concerns also were described concerning the financial impact of cancer and treatment.

The impact of breast cancer on the family was the greatest area of social concern. Women expressed intense concerns regarding fear of breast cancer in daughters, frequently described to be of more concern to the women than their own health.

Breast cancer's impact on sexuality, such as loss of the breast as well as accompanying menopausal symptoms associated with breast cancer treatment, including vaginal changes, were also described. The encouragement of peers, support groups, or other women who had experienced breast cancer was identified as a positive influence. Cultural influences, such as those that influence the practice of breast self-examination, perspectives on sexuality, and decisions regarding breast cancer treatment, were identified as social concerns.

Ferrell et al. (1998) concluded that women feel continued demands of breast cancer on their lives for many years following diagnosis. Women also described how

certain symptoms, which were of great concern to their lives, were often minimized or dismissed by health care providers.

Ferrell et al. (1998) suggested the importance of interdisciplinary care for women with breast cancer to address their many needs, such as the management of symptoms, return to work, financial concerns, and family support. Ferrell et al. also stressed the importance of ongoing nursing assessment, medical care, and the role of social workers, which was evident from the findings. Ferrell et al. (1998) also addressed the importance of focusing greater attention on the individual woman living beyond the diagnosis of breast cancer, along with the current increased focus regarding attention to early diagnosis and treatment of breast cancer. Thus, the quantity of lives preserved through breast cancer treatment and the quality of those lives will be valued.

The research of Ferrell et al. (1998) supports the current research's premise that the diagnosis and treatment of breast cancer, as well as the years that follow, involve multiple needs related to many different domains, including the physical and social domains. Ferrell et al. (1998) also support the philosophy of the

current research that the demands of breast cancer continue to have an impact on the woman's life far beyond diagnosis and treatment.

In Part II of the study by Ferrell et al. (1998), the researchers sought to explore the impact of breast cancer on the psychological well-being and the spiritual well-being domains. Ferrell et al. defined psychological well-being as "seeking a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fears of the unknown, as well as positive life changes" (p. 1).

The questions, sample, instruments, and procedures used in this study were described previously in the review of Part I of this study. Qualitative analysis utilizing content analysis was also described previously in the review of Part I of this study.

Regarding psychological well-being, Ferrell et al. (1998) identified four major themes: "concern for the future, survivorship, sources of psychological distress, and emotional responses to breast cancer" (p. 3). In the major theme relating to concerns for the future, women described the reality and fear of death and also the challenge of balancing hope and reality. Women described

their awareness and often time preoccupation with the possibility of death. Women also discussed their attempts to maintain their sense of hopefulness while balancing the reality that breast cancer could recur.

In the theme of survivorship, women described attempting to balance a constant awareness of breast cancer while keeping the disease from becoming the total focus of their attention. Women also described extreme fears related to the possibility of recurrence. Women also described the feelings of guilt they experienced with being treated successfully and with being long-term survivors when so many others had died from the disease. Women further described the struggle they still entail to maintain a sense of normalcy.

In the third theme, sources of psychological distress, identified by women in this study most often included treatment, such as bone marrow transplant, hospitalization, radiation treatment, surgery, chemotherapy, and breast reconstruction. The completion of treatment was also described as being a very stressful time in women's lives, since the women often reported feeling a sense of security or safety from breast cancer while they were undergoing treatment.

The final theme of emotions and symptoms contained women's descriptions of diverse emotions. Women concluded their moods were often improved as a result of the life-threatening illness. However, negative emotions, such as fear and depression, were also discussed. Women also "described strategies of increasing their sense of control in a situation that often seemed very out of control" (Ferrell et al., 1998, p. 6).

The domain of spiritual well-being encompassed three major themes: support of spirituality, aspects of spirituality, and alteration of life. Formal support through religious practices and religious support through churches were described by many women. Existential faith or beliefs that assisted with the women's survival were areas of informal support discussed. Other aspects of spirituality identified by women included uncertainty and hope. Uncertainty about the future was often described by women as being one of the most difficult aspects of living with breast cancer. Signs of hope were also described as very important in breast cancer survivorship. Women surviving breast cancer described how dramatically their lives had been altered as a result of cancer. They described "altered life priorities, altered life meaning,

and thoughts regarding transcendence from their current life to their death" (Ferrell et al., 1998, p. 7).

Ferrell et al. (1998) noted the fear of death appeared to be heightened in breast cancer survivors. Ferrell et al. similarly noted the theme of balancing hope with reality as being common in breast cancer. Findings from this study also confirmed the need of women with breast cancer to express emotions and seek a sense of control. Ferrell et al. concluded that breast cancer clearly had an impact on all aspects of life for the patient and family as well and that there exists a very critical need for psychological and spiritual support in meeting those needs.

This study by Ferrell et al. (1998) also supports the current research's emphasis on identifying needs in breast cancer relating to multiple domains, including the physical, psychological, and spiritual domains. This study also confirms the ideal of current research regarding the impact of breast cancer lasting beyond just the time frame of diagnosis and surgical and/or medical treatment.

Silliman, Dukes, Sullivan, and Kaplan (1998) studied older women with early-stage breast cancer. Silliman et

al. sought to answer the following questions in their research study:

- 1) Where do older women receive information regarding breast cancer care and how helpful do they perceive each of these sources to be? and
- 2) What aspects of social support are associated with older women's general and breast cancer specific emotional health outcomes? (p. 707)

The inclusion criteria for the study by Silliman et al. (1998) included women \geq 55 years, newly diagnosed with TNM Stage I or II breast cancer, and with no previous history of breast cancer. Three hundred and two (78%) of the 388 eligible women identified participated in the study. The participants ranged in age from 55 to 97 years. Forty-nine percent of the sample was married, and 34% attended religious services at least once or more weekly. An introductory letter and consent form were sent to eligible women 2 to 3 months after their definitive surgical treatment. Follow-up telephone calls were conducted by the interviewer of this study to provide additional information regarding the study, answer questions, and obtain informed consent.

Data were collected from women's surgical records and a computer-assisted telephone interview lasting 35 minutes with consenting women.

Data collected from medical records included: histology, stage, and surgeries performed (modified radical mastectomy or breast-conserving surgery). The patient telephone interview, conducted an average of 4.5 months after definitive surgical therapy, included questions regarding sociodemographic characteristics (including age, education, marital status, and religious service attendance); general health-related quality of life, measured by the Medical Outcomes Study Short Form; breast cancer specific quality of life (with response options ranging from excellent [1] to poor [5]); the presence of physician-diagnosed cardiopulmonary diseases and the frequency of associated symptoms; the perceived helpfulness of various sources of information regarding breast cancer and its treatment (with response options ranging from very helpful [1] to not applicable, did not get information from this source [5]; the kinds of help that they did not have, but wished that they had to assist them with treatment decision making and ratings of their breast cancer specialists' technical and interpersonal care [with response options ranging from excellent [1] to poor [5]. (p. 707)

Silliman et al. (1998) considered two dependent variables in their analyses, general emotional health and breast cancer specific emotional health. Silliman et al. considered indicators of social support from two categories: (a) women's informal social support: marital status and attendance at religious services and (b)

physician-patient communication associated with treatment decision making: patient's perceptions of physician communication; patients' ratings of their physician's technical and interpersonal care; and patients' perceptions of their own abilities to communicate with their physicians as independent variables. Age, two measures of health status (comorbidity and perceptions of change in health status) and type of surgery were considered as covariates by Silliman et al. (1998).

Initially, descriptive statistics were obtained on all study variables. This allowed the first study question regarding the sources of information about breast cancer accessed by women and their perceived helpfulness to be addressed. Chi-square tests were utilized to assess the relation between each source of information and women's age, education, and marital status. Factors associated with patients' general and breast cancer specific emotional health outcomes were then identified. The distributional properties of the two dependent variables and the array of independent variables were investigated in the first phase of analysis. Next, bivariate relations between the independent variables and each dependent variable using two independent sample Student's *t* tests

and correlation analysis were examined. In the final analysis stage, multiple linear regression models relating the two dependent variables, considered separately, to select independent variables were developed.

Silliman et al. (1998) determined the mean scores of health status indicators were as follows: "comorbidity = 7.06 (range, 3-20); health transitions = 44.95 (range, 0-100); general emotional health = 74.01 (range, 12.5-100); and breast cancer specific emotional health = 65.95 (range, 6.25-100). Twenty-one percent of these women underwent modified radical mastectomy" (p. 708). Silliman et al. (1998) identified the following findings:

Nearly all women rated information that was provided by their breast cancer physicians as very or somewhat helpful. Written materials provided by breast cancer physicians also were frequently rated as very or somewhat helpful. Women's marital status, religious service attendance, ratings of their physician's technical and interpersonal care, and perceptions of their abilities to communicate with their physicians were significantly associated with both general and breast cancer specific emotional health outcomes (all $p < .05$). (p. 706)

Silliman et al. (1998) concluded that older women relied heavily on their physicians for information. A finding of concern by Silliman et al. (1998) was that women in their study perceived their primary care

physicians to be one of the least helpful sources of information regarding breast cancer care. Silliman et al. emphasized the importance of primary care physicians having access to up-to-date, high quality information regarding cancer care and also having an understanding of treatment as well as follow-up issues appropriate for different subsets of patients. This is especially important as our nation moves toward models of care that increasingly rely on primary care physicians. Silliman et al. also noted older patients frequently rely on their physicians to make treatment decisions for them; therefore, physicians may need to direct more effort towards involving their older patients in care decisions. Findings from this study also identified a substantial proportion of women who indicated they would have benefitted from having someone with them at appointments when treatment options were discussed and knowing what questions to ask in relation to breast cancer and breast cancer treatment. Silliman et al. (1998) stated the importance of developing methods to enhance physician-patient communications in order to assist in outcome improvements.

The study by Silliman et al. (1998) offers some validation to the current study. Several areas of need were identified in this study. These identified areas of need correlate with several of the needs under investigation in the current study. However, the current study seeks to identify areas of need occurring in the diagnosis and treatment of breast cancer and in the years that follow, whereas the study by Silliman et al. (1998) investigated needs occurring in the early stages of breast cancer treatment.

The study by Graydon et al. (1997) sought to determine the information needs of women during their early treatment for breast cancer. This study assessed the needs of women at two points during the chemotherapy and radiation therapy regimens.

The sample of this study was obtained from a large urban hospital and regional cancer center in Canada. Purposive sampling was used to recruit women who were being treated by chemotherapy, radiation therapy, or surgery.

All the women had a recent diagnosis of breast cancer and were English speaking. Women recruited into the chemotherapy group had breast-conserving surgery (BCS) and were receiving either their first course (C1) of

chemotherapy or their sixth (C2). Women in the radiation therapy group had BCS and were in either their first week of radiation therapy (R1) or at a follow-up visit after a first course of radiation therapy (R2). Women in the surgery group were awaiting hospital discharge after BCS or mastectomy. A woman could be a subject in only one group. (p. 60)

Seventy women comprised the sample for this study.

The chemotherapy group contained 25 women, 11 in C1 and 14 in C2. The radiation therapy group was comprised of 23 women: 12 in R1 and 11 in R2. There were 22 women in the surgery group, 13 had BCS and 9 mastectomy. The mean age of the sample was 49.7 years, with the women ranging in age from 21 to 91 years. Sixty-five percent of the women in the sample were married, 76% had completed high school, and 61% had household incomes of at least \$40,000.

The breast cancer version of the Toronto Informational Needs Questionnaire (TINQ-BC) was used to measure information needs in this study. Each item on the TINQ-BC was rated on a five-point scale from 1 (not very important) to 5 (extremely important). There were 51 items on the TINQ-BC measuring five subscales: disease, investigative tests, treatments, physical, and psychosocial.

All women eligible for this study were invited to participate once approval was received from the Institutional Review Board. Prior to data collection, written informed consent was obtained. Data collection took approximately 40 minutes and involved the women completing the TINIQ-BC. To identify the areas of greatest information need from the TINIQ-BC, percentage means were calculated.

Graydon et al. (1997) found that all women had high information needs regardless of type of treatment received. Disease, investigative tests, and treatments were the areas of highest information needs, according to the findings of Graydon et al. (1997). After examining individual items on the TINIQ-BC, Graydon et al. (1997) discovered that all women wanted information about recurrence; specifically the women wanted to know if the cancer would recur and how to determine if the cancer had recurred. Graydon et al. (1997) also found that younger women had a greater need for information.

Graydon et al. (1997) concluded that women with breast cancer wanted information, regardless of where they were in the treatment trajectory and that nurses needed to assess the information needs of all women with breast

cancer, not just those women who were newly diagnosed. Graydon et al. also concluded that specific information on recurrence should be offered to all women with breast cancer, since recurrence was a topic on which all women wanted information. Graydon et al. recommended that future research should focus on how best to meet the information needs of women with breast cancer.

Graydon et al. (1997) acknowledged that information needs may change over time and, therefore, assessed the needs of women at different times of treatment for this study. In this respect, the study by Graydon et al. is similar to the current study since the current study is attempting to identify needs of women in various phases of breast cancer treatment, although the study by Graydon et al. (1997) did not ascertain the information needs of women beyond the treatment phase.

The review of the literature gave evidence of the existence of numerous factors associated with breast cancer classification, treatment, and results. The review of the literature also acknowledged the emotional and physical side effects associated with the diagnosis of breast cancer and the subsequent treatment of breast cancer. The review of the literature suggested different

side effects and perceptions concerning overall health occur with breast cancer treatment. Hoskins (1997) concluded that adjustment to the diagnosis and treatment of breast cancer occurred over a period of time. The majority of the available research is limited to the phases of the time of diagnosis of breast cancer and the time of treatment of breast cancer. More research is needed to determine the impact of breast cancer in the years following treatment.

This review of literature revealed that scant knowledge exists regarding the type of information women with a recent diagnosis of breast cancer need to deal with their illness. Therefore, more research is needed to ascertain what needs women have at the time of diagnosis of breast cancer and in the treatment phase.

Breast cancer impacts all aspects of a woman's life. Ferrell et al. (1998) concluded that greater attention has been focused on early detection and aggressive treatment of breast cancer in recent years. Ferrell et al. concluded that less attention has been given to the equally important realms of the physical, psychological, social, and spiritual aspects of breast cancer treatment. More research is needed to address the holistic needs of women

with breast cancer at the time of diagnosis, during treatment, and in the years following treatment.

Chapter III

The Method

The purpose of this study was to identify the needs of women with breast cancer during phases of treatment. The methodology for the study will be discussed in this chapter.

Design of the Study

The design of this study was descriptive exploratory. Descriptive research seeks to describe rather than explain phenomena. Exploratory research seeks to explore the dimensions of the phenomenon, the manner in which the phenomenon is manifested, and the relationship of other factors with the phenomenon (Polit & Hungler, 1995). This researcher sought to determine the needs of women with breast cancer at the time of diagnosis of breast cancer, during treatment of breast cancer, and following treatment of breast cancer.

Variables. The variables of interest in this study were the needs of women with breast cancer at the time of

diagnosis, during treatment, and following treatment of breast cancer.

Setting, Population, and Sample

The setting for this study was a cancer support center located in a four-story medical office building in a southeastern city. The population of the metropolitan area of the city is approximately 1 million residents. The cancer support center is funded by a nonprofit cancer foundation. Approximately 25 people attend the center daily. Clients of the support center were often referred to the center by a physician or other health care provider or were self-referred. A convenience sampling design was utilized in this study, with a target sample size of 12 legally competent adult subjects. The sample was from a mostly white, middle-class, suburban population, which was relatively representative of the catchment group for the center. The sample consisted of subjects who met the inclusion criteria and agreed to participate in the study. The target population was women with breast cancer, with the inclusion criteria being women diagnosed with primary breast cancer at least one year prior to data collection,

who attended the cancer support center and received breast cancer treatment.

Methods of Data Collection

Instrumentation. The instruments used for data collection in this study were the Massey Subject Profile and the Massey Questionnaire (see Appendices A and B). These instruments were developed by the author and were reviewed by a panel of experts to determine face validity. The Massey Subject Profile consisted of demographic questions concerning age, racial background, level of education completion, marital status, age of any children, annual household income, and current employment status. The Massey Subject Profile also contained 10 questions regarding initial tumor status and initial breast cancer treatment, as well as breast cancer recurrence or metastasis. The Massey Questionnaire consisted of 12 questions regarding needs at the time of diagnosis of breast cancer, during treatment of breast cancer, and following treatment of breast cancer. The needs assessed by the Massey Questionnaire consisted of questions related to information needs, comfort needs, actions needed, concerns, and fears. Nine multiple-choice questions and

three open-ended questions were utilized for the variables in the study. Content validity was assessed by a panel of experts who determined that needs were related to the physical, spiritual, emotional, social, and developmental realms of subjects' needs.

Procedures. During the fall of 1998 the researcher received verbal permission from the director of the cancer support center to utilize clients of the center as sample subjects. Permission was obtained from the Mississippi University for Women's Committee on Use of Human Subjects in Experimentation (IRB) (see Appendix C). Following permission from the IRB, written permission from the director of the cancer support center was obtained. Data collection took place between May and June of 1999. Written informed consent was obtained from each subject prior to data collection (see Appendix D). Participation in the study by each subject was voluntary. Each subject's identity in the study was anonymous. The Massey Subject Profile and the Massey Questionnaire were identified by a subject number. The subject number was not assigned to any sample numbers. Data collection consisted of each participating subject completing questionnaires distributed by the researcher. The questionnaires were

completed at the center following breast cancer support group meetings and were retrieved following each respective meeting by the researcher.

Methods of Data Analysis

Descriptive statistics including frequency distributions and percentages were utilized in this study. Central tendency measures using the mean and median mode also were used in this study. Content analysis using themes as the unit of analysis was utilized for the narrative data in this study. Recorded occurrences of each theme were enumerated for quantification.

Limitations

The Massey Subject Profile and the Massey Questionnaire were utilized in this study. These instruments were reviewed by a panel of experts and face validity was determined. The use of a convenience sample of women attending a breast cancer support center limits the generalization of the findings of this study to another population of women with breast cancer. The sample size, racial characteristics, income, and education level, as well as the geographical location of this study also may limit the generalization of this study.

Chapter IV

The Findings

The purpose of this study was to identify the needs of women with breast cancer during phases of treatment. The design utilized in this study was descriptive exploratory. There was one research question: What are the needs of women with breast cancer during the phases of treatment? In this chapter, a description of the sample and analysis of the data in relation to the research question are discussed.

Description of the Sample

Convenience sampling was utilized for data collection in this study. The participants in this study attended a cancer support center in a southeastern metropolitan city. The sample consisted of 12 women, all of whom had been diagnosed with breast cancer at least one year prior to data collection and had received some form of breast cancer treatment.

The sample ranged in age from 40 to 71 years, with the mean age of 51 years. Race, or ethnic origins, of the sample was 9 (75%) Caucasian, 2 (17%) African American, and 1 (8%) Hispanic. The highest level of education completed for the sample ranged from 3 (25%) high school graduates, 3 (25%) having at least some college, 2 (17%) college graduates, and 4 (33%) with postgraduate degrees.

Of the sample, 9 (75%) were married, 2 (17%) were divorced, and 1 (8%) was single and had never been married. None of the respondents who were divorced or single had a significant other living with them. All except one of the respondents had children. The age range of the children of the respondents varied from 1 to 2 years to greater than 30 years.

The annual household income level for the sample ranged from \$26,000 to > \$100,000, with the typical annual household income being \$51,000 to \$75,000. Eight (67%) of the sample were currently employed, and 4 (33%) of the sample were not currently employed.

The time span from diagnosis of breast cancer to time of data collection for the sample ranged from 1 to 17 years, with the mean time span being 6.6 years. The age of the sample at the time of diagnosis of breast cancer

ranged from 29 to 58 years of age, with the mean age being 45 years.

Subject data from the Massey Subject Profile concerning tumor stage and medical treatment of the sample are listed in Table 1. Cancer cells were found in the axillary lymph nodes with the initial surgery of 6 (50%) of the sample. The tumor estrogen receptor status of the sample was as follows: 7 (58%) estrogen receptor positive, 3 (25%) estrogen receptor negative, and 2 (17%) responded "I don't know."

Table 1

Subject Data Concerning Tumor Stage and Medical Treatment of the Massey Subject Profile Using Frequencies and Percentages

Demographic data	f	%
Tumor stages ^a		
T1	4	33.0
T2	3	25.0
T3	2	17.0
Don't know	3	25.0
Medical treatment ^b		
Radiation and chemotherapy	3	25.0
Chemotherapy only	3	25.0
Chemotherapy and Tamoxifen	3	25.0
Surgical treatment only	2	17.0
Omit	1	8.0

^an = 12. ^bn = 12.

Mastectomy was the initial surgical treatment in 9 (75%) of the sample, and lumpectomy was the initial surgical treatment in 3 (25%) of the sample. Since initial diagnosis of breast cancer, 3 (25%) of the sample has had a recurrence or metastasis of cancer, 8 (73%) have not, and 1 (8%) of the sample omitted this response.

Of the sample, 8 (67%) of the initial treatment for breast cancer was suggested by a physician, 3 (27%) suggested their initial treatment for cancer themselves, and there was 1 (8%) omit on this response. Of the sample, all educated themselves on breast cancer during at least one of the treatment phases (see Table 2). Nine (75%) of the sample responded they were satisfied with their breast cancer surgical and medical treatment choices. Of the 2 (17%) of the sample who were not satisfied, the explanations given were "not being given enough time after being diagnosed with breast cancer to decide on surgical and medical treatment choices" and "wishing a lumpectomy instead of mastectomy had been performed." One (8%) of the sample omitted this response.

Table 2

Responses of Self-Education of Breast Cancer on the Massey Subject Profile Expressed in Frequencies and Percentages

Period of self-education	f ^a	%
Before diagnosis only	1	8.0
Before diagnosis and during treatment	1	8.0
Before diagnosis, during treatment, and after treatment	2	17.0
During treatment only	4	33.0
During treatment and after treatment	2	17.0
After treatment only	2	17.0

^aN = 12.

Results of Data Analysis

The Massey Questionnaire was used to gather data for this research study. Descriptive statistics regarding frequencies and percentage were established for each item on the research instrument. For the three sets of open-ended items, the content was analyzed and themes were then developed. Descriptive statistics regarding frequencies and percentages were then utilized on each theme in the

three sets of open-ended items. The frequency for the open-ended items was calculated from the total number of respondents in the sample since the total sample did not respond to all of the open-ended items. Although in each of the multiple-choice items, the respondent was asked to choose the answer that best applies, a few respondents chose more than one answer, citing that several answers were of equal importance to them. Therefore, the total number of answers to each item was tabulated, and then descriptive statistics regarding frequencies and percentages were utilized.

Theme frequency and percentage responses to the first two sets of open-ended items on the Massey Questionnaire are displayed in Tables 3 and 4. In the sample, several clarified that they listed information and actions that had actually occurred in responses to these two sets of open-ended items.

Table 3

Theme Frequency and Percentage Response to Most Helpful Information During Treatment Phases for Breast Cancer on the Massey Questionnaire

Information and treatment phase	f	%
At the time of diagnosis of breast cancer ^a		
Statistical information/general information on breast cancer, treatment, and treatment options	8	73.0
Prayer offered on my behalf	1	9.0
Knowing good physician	1	9.0
Information on good nutrition and on support groups	1	9.0
During treatment for breast cancer ^b		
Information on different types of breast cancer and treatment options/information	4	50.0
Information on what to expect/diet	1	12.5
Information on support groups	1	12.5
Information on health maintenance and on how to look good while on chemotherapy	1	12.5

(table continues)

Table 3 (Continued)

Information and treatment phase	f	%
Information on alternative therapies	1	12.5
After treatment for breast cancer ^c		
Information on exercise	1	12.5
Information on reconstruction options	1	12.5
Information on prevention	1	12.5
Information about lymphedema and about future medical insurance	1	12.5
Information on detecting recurrence (signs/symptoms of recurrence)	2	25.0
Information on support groups	1	12.5
Information on alternative therapies	1	12.5

^an = 11. ^bn = 8. ^cn = 8.

Table 4

Theme Frequency and Percentage Responses to Most Helpful Actions Taken by Self or Others During Treatment Phases for Breast Cancer on the Massey Questionnaire

Helpful actions and treatment phase	f	%
At the time of diagnosis of breast cancer ^a		
Contact with and support from breast cancer survivors	4	40.0
Support from family and church	1	10.0
Maintaining positive and proactive attitude	2	20.0
Getting more education on breast cancer	1	10.0
Compassion	1	10.0
Help with children, household cleaning, cooking	1	10.0
During treatment for breast cancer ^b		
Mental and emotional support from family, church, friends, and co-workers	3	43.0
Belonging to support group	2	29.0
Leave of absence from work (having the FMLA)	1	14.0
Feeling good about physician	1	14.0

(table continues)

Table 4 (Continued)

Treatment phase	f	%
After treatment for breast cancer ^c		
Belonging to support groups	4	66.0
Therapy concerning chemotherapy induced amenorrhea	1	17.0
Support from family, friends, and church family	1	17.0

^an = 10. ^bn = 7. ^cn = 6.

Tables 5, 6, and 7 list the frequency and percentage responses to the items regarding the greatest need during the phases of treatment. In the sample, several listed as an addendum to the responses the importance of support throughout the phases of treatment. Support coming from husbands, families, friends, support groups, and other survivors of breast cancer were specifically listed as a response to them items.

Table 5

Frequency and Percentage Response to Greatest Need at the
Time of Diagnosis of Breast Cancer on the Massey
Questionnaire

Greatest need	f ^a	%
Support	5	28.0
Education concerning breast cancer, treatment, and prognosis	3	17.0
Spiritual support, counseling, or guidance	3	17.0
Information about available surgeons and/or oncologists in your area	3	17.0
Time with family	1	5.0
Solitary time	2	11.0
Other Needed more time after diagnosis (of breast cancer) to decide on treatment choices	1	5.0

^aN = 18.

Table 6

Frequency and Percentage Responses to Greatest Need During Treatment for Breast Cancer on the Massey Questionnaire

Greatest need	f ^a	%
Support	4	17.4
Education about side effects of treatment	3	13.0
Relief measures for side effects, other than pain	1	4.3
Spiritual support, counseling or guidance	4	17.4
Time with family	2	9.0
Solitary time	1	4.3
Financial support, resources	1	4.3
Relief from work, or decreased work schedule	3	13.0
Relief from household upkeep responsibilities	3	13.0
Other		
Stress relief/techniques	1	4.3

^aN = 23.

Table 7

Frequency and Percentage Response to Greatest Need After
Treatment for Breast Cancer on the Massey Questionnaire

Greatest need	f ^a	%
Support	6	26.0
Education about signs/symptoms of cancer recurrence or metastasis	5	22.0
Financial support, resources	1	4.0
Spiritual support, counseling, or guidance	4	17.0
Time with family	3	13.0
Solitary time	2	9.0
Other		
Information on how to regain strength and work relief	1	4.5
Help dealing with bouts of fear of recurrence	1	4.5

^aN = 23.

The frequency and percentage responses to the items regarding the greatest concern during the phases of treatment are listed in Tables 8, 9, and 10. Three items on the Massey Questionnaire related to whether the greatest concerns during the phases of treatment were related to a fear of dying from cancer. The responses were as follows: The greatest concern at the time of diagnosis of breast cancer was related to a fear of dying from cancer in 9 (75%) of the sample. The greatest concern during treatment for breast cancer was related to a fear of dying from cancer in 4 (33%) of the sample. The greatest concern after treatment for breast cancer was related to a fear of dying from cancer in 4 (33%) of the sample.

The theme frequency and percentage responses to the third set of open-ended questions on the Massey Questionnaire are listed in Table 11. As in the other two sets of open-ended questions, in the sample, several stated they listed a response to the item that had actually occurred.

Table 8

Frequency and Percentage Response to Greatest Concern at the Time of Diagnosis of Breast Cancer on the Massey Questionnaire

Greatest concern	f ^a	%
Concern for own physical health	3	13.6
Concern for spouse/significant other	3	13.6
Concern for children	5	23.0
Concern about performing household responsibilities	1	4.5
Concern about finances	1	4.5
Concern about treatment choices	3	13.6
Concern for spiritual help	3	13.6
Other		
Finding the right doctor	1	4.5
Needed more time to decide on treatment choices	1	4.5
Not wanting to be a burden on family (parents/siblings)	1	4.5

^aN = 22.

Table 9

Frequency and Percentage Response to Greatest Concern
During Treatment for Breast Cancer on the Massey
Questionnaire

Greatest concern	f ^a	%
Concern for own physical health	3	17.0
Concern for spouse/significant other	2	11.0
Concern for children	4	22.2
Concern for finances	1	5.6
Concern about performing household responsibilities	1	5.6
Concern about pain	1	5.6
Concern about appropriate treatment choices	2	11.0
Concern for spiritual help	2	11.0
Other		
Concern about energy level	1	5.5
Concern about not wanting to be a burden on family members	1	5.5

^aN = 18.

Table 10

Frequency and Percentage Response to Greatest Concern
After Treatment for Breast Cancer on the Massey
Questionnaire

Greatest concern	f ^a	%
Concern for own physical health	2	10.0
Concern for spouse/significant other	1	5.0
Concern for children	2	10.0
Concern about performing work responsibilities	1	5.0
Concern for finances	1	5.0
Concern about performing household responsibilities	1	5.0
Concern for spiritual self	3	15.0
Concern about body image	2	10.0
Concern about cancer recurrence or metastasis	6	30.0
Other		
Increasing energy level and losing weight	1	5.0

^aN = 20.

Table 11

Theme Frequency and Percentage Response to What Brought
Most Comfort During Phases of Treatment for Breast Cancer
on the Massey Questionnaire

Source of support and treatment phase	f	%
At the time of diagnosis of breast cancer ^a		
Support from family and church	5	36.0
Support group	4	28.5
Support from physician (including spiritual support)	1	7.0
More information on breast cancer	4	28.5
During treatment for breast cancer ^b		
Support from family, church	4	40.0
Support group	5	50.0
Support from physician	1	10.0
After treatment for breast cancer ^c		
Support group	5	50.0

(table continues)

Table 11 (Continued)

Source of support and treatment phase	f	%
Support from family, church, and God	4	40.0
Losing weight and improving energy level	1	10.0

^an = 14. ^bn = 10. ^cn = 10.

Chapter V

The Outcomes

Breast cancer has been documented as the second leading cause of death from cancer in American women. Various treatments exist for breast cancer. The diagnosis of breast cancer and any ensuing treatment can be anxiety-provoking, and multiple needs are perceived during these phases. The purpose of this descriptive exploratory study was to identify the needs of women with breast cancer during phases of treatment. One research question guided this study: What are the needs of women with breast cancer during the phases of treatment? The theoretical framework utilized for this study was the Neuman Systems Model (Neuman, 1996).

The convenience sample in this study consisted of 12 women diagnosed with primary breast cancer at least a year prior to data collection attending a cancer support center in a southeastern metropolitan city. The Massey Subject Profile and the Massey Questionnaire were the instruments utilized for data collection. Descriptive statistics

including frequency distributions and percentages and content analysis were utilized in this study.

Summary of Findings

The sample consisted of 12 women ranging in age from 40 to 71 years, with the mean age for the sample being 51 years. Of the sample, 9 were Caucasian, 2 were African American, and 1 was Hispanic. Of the sample, all had completed high school, with 4 of the sample having postgraduate degrees. Nine (75%) of the sample were married, and all except one of the sample had children. The typical annual household income for the sample was \$51,000 to \$75,000. Eight (67%) of the sample were currently employed.

The mean time span from diagnosis of breast cancer to data collection for the sample was 6.6 years. The mean age of the sample at the time of diagnosis of breast cancer was 45 years of age. Results from the Massey Questionnaire regarding tumor stage revealed a fairly even distribution between T1, T2, and T3. Six (50%) of the sample had cancer cells found in their axillary lymph nodes with the initial surgery. Seven (58%) of the sample had estrogen receptor positive tumors.

The initial surgery for the sample was mastectomy in 9 (75%) and lumpectomy in 3 (25%) of the sample. The medical treatment for the sample was as follows: radiation and chemotherapy (n = 3, 25%), chemotherapy only (n = 3, 25%), chemotherapy and Tamoxifen (n = 3, 25%), surgical treatment only (n = 2, 17%), and 1 (8%) omitting this response. Three (25%) of the sample have had recurrence or metastasis of cancer since initial diagnosis.

A physician suggested the initial treatment for breast cancer in 8 (67%) of the sample. Of the sample, all have educated themselves on breast cancer during varying phases of treatment, with the majority (n = 4, 33%) educating themselves on breast cancer during treatment only. Nine (75%) of the sample responded they were satisfied with their breast cancer surgical and medical treatment choices.

Data analysis revealed themes encompassing statistical and general information on breast cancer, treatment, and treatment options that would have been most helpful at the time of diagnosis of breast cancer in 8 (75%) of the sample, and during treatment for breast cancer in 4 (50%) of the sample respondents. The themes that emerged through content analysis of information that

would have been most helpful after treatment for breast cancer all revolved around the aftereffects of breast cancer treatment. This involved information on reconstruction options, lymphedema and future medical insurance, signs and symptoms of recurrence, and how to detect recurrence as well as more tertiary prevention measures, such as exercise, prevention, alternative therapies, and support groups.

The most prominent theme emerging after data analysis regarding actions taken by self or others that would have been most helpful was support coming in the form of a support group with other survivors and/or from spouses, other family members, coworkers and friends during all phases of treatment. Another theme regarding actions that would have been or were most helpful at the time of diagnosis of breast cancer was maintaining a positive and proactive attitude. Another emerging theme revealed as actions that would have been most helpful after treatment for breast cancer was counseling concerning chemotherapy related amenorrhea.

The most frequently listed greatest need during all the phases of treatment for breast cancer was support coming from husbands, families, friends, support groups,

and other survivors of breast cancer. Education concerning breast cancer, treatment and prognosis, spiritual support, counseling or guidance, and information about available surgeons and/or oncologists in immediate area were also listed frequently as greatest needs at the time of diagnosis of breast cancer. Spiritual support, counseling, or guidance was listed equally as frequently as support coming from the other areas (e.g., the greatest need during treatment for breast cancer). After both spiritual support and support coming from other means, the most frequently listed greatest needs during treatment for breast cancer were education about side effects of treatment, relief from work, or decreased work schedules, and relief from household upkeep responsibilities. After treatment for breast cancer, the most frequently listed greatest need after support was education about signs/symptoms of cancer recurrence or metastasis and following this, spiritual support, counseling, or guidance.

The most frequently listed concern both at the time of diagnosis and during treatment for breast cancer was concern for children. The most frequently listed concern after treatment for breast cancer was concern about cancer

recurrence or metastasis, followed by concern for spiritual self. The greatest concern listed was related to a fear of dying from cancer in 9 (75%) of the sample at the time of diagnosis of breast cancer.

Themes emerging from content analysis of what would have brought the most comfort (some respondents listed things that did bring them the most comfort) during the phases of treatment for breast cancer follow. Support from family and church was listed most frequently as what would have or did bring the most comfort at the time of diagnosis of breast cancer, followed by having a support group of other breast cancer survivors, and having more information on breast cancer. A support group of other breast cancer survivors was listed most frequently as what did or would have brought the most comfort during treatment and after treatment for breast cancer, followed by support from family, church, and God.

Discussion

The sample in this study had similar medical and adjuvant systemic treatments as those listed in the studies by Bastert et al. (1998), Hoskins (1997), and Kini et al. (1998). The medical and surgical treatment of the

sample in this study fell under secondary prevention in the Neuman Systems Model (Neuman, 1996). Overall, the sample in this study was very knowledgeable concerning their breast cancer classifications such as tumor stage, axillary lymph node status with their initial surgeries and estrogen receptor status of their tumors as evidenced by their responses to questions regarding these classifications on the Massey Subject Profile.

The findings in this study supported the conclusion of the study by Hoskins (1997) that adjustments to the diagnosis and treatment of breast cancer occurred over a period of time. Statistical and general information regarding breast cancer, treatment, and treatment options were found to be the most predominant theme concerning information that would have been most helpful at the time of diagnosis of breast cancer and during treatment for breast cancer. This finding was consistent with the study findings by Graydon et al. (1997).

Information concerning signs and symptoms of breast cancer recurrence and how to detect recurrence was a theme that emerged through content analysis as being most helpful after treatment for breast cancer. The study by Graydon et al. (1997) reported similar findings, although

Graydon et al. (1997) did not ascertain the information needs of women beyond the treatment phase.

Another theme that emerged in the findings of this study regarding information that would have been most helpful after treatment for breast cancer included information concerning alternative therapies and prevention. These areas fell under tertiary prevention in the Neuman Systems Model (Neuman, 1996). Alternative therapies and prevention measures would most likely assist the women with breast cancer in this sample to feel more empowered after treatment for breast cancer; to feel as if they were continuing to do something to keep their cancer under control. Women frequently have reported heightened anxiety toward the end of breast cancer treatment, indicating that the cancer treatment had made them feel their cancer was under control (Keller, 1998). Graydon et al. (1997) acknowledged that information needs might change over time with women with breast cancer. This acknowledgment by Graydon et al. (1997) was verified by the findings in this study.

Support coming in the form of a support group with other survivors and from spouses, other family members, coworkers and friends was a resounding predominant theme

listed as actions taken by self or others that would have been most helpful during all phases of treatment. In the study by Ferrell et al. (1998), the encouragement of peers, support groups, or other women who had experienced breast cancer were identified as positive influences.

A theme concerning actions taken by self or others that would have been most helpful after treatment for breast cancer was therapy concerning chemotherapy related amenorrhea. This issue greatly affects younger women and can have an enormous impact on the quality of life for the women affected. Chemotherapy related amenorrhea is often irreversible (Bines & Gradishar, 1997). Therefore, the impact of chemotherapy related amenorrhea continues into the long-term survivorship for the women affected, bringing about early menopausal symptoms at an early age and cutting short their reproductive years.

Support coming from husbands, family, friends, support groups, and from other survivors of breast cancer was the most frequently listed greatest need during all phases of treatment for breast cancer. This current finding supports the findings by Ferrell et al. (1998) who identified the positive influence of the encouragement of

peers, support groups, or other women who had experienced breast cancer.

During the treatment of breast cancer, spiritual support, counseling, or guidance were listed as frequently as the other forms of emotional support as being the greatest need. Ferrell et al. (1998) also concluded that there exists a very critical need for spiritual support in meeting the needs of women with breast cancer.

Concern for children was listed most frequently as the greatest concern at the time of diagnosis and during treatment for breast cancer. The study by Ferrell et al. (1998) had similar findings, reporting that one of the greatest areas of social concern in women with breast cancer was related to the impact of breast cancer on the family. Women with breast cancer who have small children are often concerned about whether they will live long enough to see their children grown up and the impact breast cancer may have on the children's lives and well-being.

The fear of dying from cancer appeared to be heightened at the time of diagnosis of breast cancer in this sample. Nine (75%) of the sample stated their greatest concerns at the time of diagnosis of breast

cancer were related to a fear of dying from cancer. The fear of dying from cancer declined in this sample during treatment and after treatment for breast cancer, with 4 (33%) of the sample stating their greatest concerns at these times were related to a fear of dying from cancer. The findings from this study regarding fear of dying differ from the findings by Ferrell et al. (1998) whose sample was at least a year beyond diagnosis of breast cancer at the time of data collection. Ferrell et al. (1998) noted the fear of death appeared to be heightened in breast cancer survivors. The fear of dying from cancer declined over time, even during the time of treatment for breast cancer in this study. This may have been due to the fact that the women in this sample attended a support group of survivors of breast cancer. Talking over any fears or concerns about breast cancer or dying with other women experiencing, or having survived, the same thing probably assisted the women in this sample to decrease their fears about dying from cancer.

The most frequently listed concern after treatment for breast cancer was concern about cancer recurrence or metastasis. This finding correlated with the finding by Ferrell et al. (1998). The next most frequent concern

after treatment for breast cancer was concern for spiritual self. Women have described the importance of spiritual support and spirituality in assisting them in facing breast cancer. Many women reported how spirituality enabled them to find meaning in their lives, despite the life-threatening illness of breast cancer (Ferrell et al., 1998). Interestingly, the concern for spiritual self was greater after treatment for breast cancer, while the fear of dying from cancer was less during this same time in the sample of this study. The women in this study may have been addressing the concern for their spiritual self during this time. Therefore, they may have felt more at peace with their spirituality and less anxious about the uncertainty of the future, thereby lessening their fear of dying from cancer.

Support from family and church either did or would have brought the most comfort at the time of diagnosis of breast cancer in this sample. In the study by Ferrell et al. (1998), women with breast cancer described religious support as being an area used for formal support.

Support groups of other breast cancer survivors was listed most frequently as what did or would have brought the most comfort during treatment and after treatment for

breast cancer. The positive influence of support groups or other women who had experienced breast cancer on women with breast cancer was also identified by Ferrell et al. (1998).

Support from family, church, and God were listed next as what did or would have brought the most comfort during treatment and after treatment for breast cancer. The importance of spiritual support during all the phases of treatment of breast cancer in the sample of this study cannot be overlooked. Spiritual support was listed with equal frequency in this study as support coming from husbands, families, friends, support groups, and other survivors of breast cancer as the greatest need during the treatment for breast cancer. The emphasis on spiritual support in this study may be due to the setting of this study being located in the so-called "Bible Belt," where a large emphasis is placed on spiritual aspects, church, and God. Therefore, spiritual support and spiritual aspects may have played a larger part in the lives of the women in this study than perhaps they would have in a study carried out in another geographical area.

Breast cancer impacts all aspects of a woman's life. The needs of the women with breast cancer in this study

encompassed all system variables (physiological, psychological, sociocultural, developmental, and spiritual) in the Neuman Systems Model (Neuman, 1996) throughout all phases of treatment. It is important to address the needs of women with breast cancer in a wholistic manner throughout all phases of treatment. By meeting the needs of women with breast cancer, tertiary prevention under the Neuman Systems Model would take place, thereby assisting the women in reconstitution and mobilization of the system toward wellness (Neuman, 1996).

Conclusions

Based on statistical findings and content analysis of items in this study, the following conclusions were made:

1. Statistical and general information on breast cancer, treatment, and treatment options are information that would have been most helpful at the time of diagnosis of breast cancer and during treatment for breast cancer.

2. Information regarding the physical aftereffects of breast cancer treatment, such as reconstruction options, lymphedema, signs and symptoms of recurrence, and how to detect recurrence as well as more tertiary prevention measures, such as exercise, prevention, alternative

therapies, and support groups would have been most helpful after treatment for breast cancer.

3. Support coming in the form of a support group with other breast cancer survivors and/or from spouses, other family members, coworkers, and friends were actions taken by self or others that would have been most helpful during all phases of treatment for breast cancer.

4. The greatest need during all phases of treatment for breast cancer was support coming from husbands, families, friends, support groups, and other survivors of breast cancer. Spiritual support was equally the greatest need as support coming from other forms during treatment for breast cancer.

5. The greatest concern at the time of diagnosis and during treatment for breast cancer was concern for children.

6. The greatest concern after treatment for breast cancer was concern about cancer recurrence or metastasis.

7. The greatest concern at the time of diagnosis of breast cancer was greatly related to a fear of dying from cancer.

8. Support from family and church would have brought, or did bring, the most comfort at the time of diagnosis of breast cancer.

9. Support groups of other breast cancer survivors would have brought, or did bring, the most comfort during and after treatment for breast cancer.

10. The importance of spiritual support was mentioned predominantly throughout all the phases of treatment for breast cancer.

Implications for Nursing

Findings in this study have numerous implications for advanced nursing practice. Breast cancer impacts all areas of life in the women affected. Nurse practitioners need to treat clients with breast cancer in a wholistic manner, addressing the physiological, psychological, sociocultural, developmental, and spiritual needs of the client. Nurse practitioners need to have open communication with the client with breast cancer and allow the client to openly discuss the impact cancer is having on all the domains in their lives. Nurse practitioners should encourage the client with breast cancer to express their feelings and concerns.

Nurse practitioners need to be aware of the effects of breast cancer on the family and address these issues. Nurse practitioners need to educate the entire family on the impact of breast cancer on the client. This will foster more support and understanding from the entire family and broaden the client's support base.

There is a high probability that nurse practitioners will be caring for the client at the time of diagnosis of breast cancer. The findings of this study can be utilized to anticipate what information and actions would be most beneficial to the client at the time of diagnosis of breast cancer, and also to anticipate the client's greatest needs and concerns at this time. The nurse practitioner needs to assess the adequacy of the client's support base at the time of diagnosis of breast cancer and address any needs for psychosocial interventions. Clients should be referred to support groups in the area at this time also.

The findings from this study can be utilized by the nurse practitioner to anticipate the information needs, as well as other needs and concerns of the client with breast cancer during all the treatment phases. Nurse practitioners need to be aware of the impact breast cancer

and breast cancer treatment have on the long-term survivors of breast cancer and approach the issues realized in this study with the client.

The nurse practitioner needs to be educated on the available stress-relief and safe alternative therapies that may be available to the client with breast cancer. The nurse practitioner needs to maintain an open mind and supportive attitude with clients who may be using safe alternatives in conjunction with traditional therapies.

Nurse practitioners need to be aware of the importance placed on spiritual support and spirituality in many clients with breast cancer. The client, if so desired, should be encouraged and supported in utilizing spiritual support. It may be necessary for the nurse practitioner to contact the client's clergy for them, if so desired by the client. With this action, the nurse practitioner can be instrumental in initiating the spiritual support base for the client.

Recommendations for Further Studies

Based on the findings of this study, the following recommendations are made for future nursing research:

1. Replication of this study using a larger sample.
2. Replication of this study in another geographical area.
3. Further research on the impact of spiritual support and spirituality on breast cancer.
4. Further research into the effect of alternative therapies on breast cancer and prognosis.
5. Further research regarding the impact of belonging to a support group on breast cancer and prognosis.
6. Further research concerning the impact of breast cancer on the family, specifically spouses and children.

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APPENDIX A
MASSEY SUBJECT PROFILE

Massey Subject Profile

Today's Date: _____

Subject #: _____

Instructions: Please answer each of the following questions by placing a check (✓) by your response.

1. What is your current age? _____
2. What is your racial background?
____ Caucasian
____ African American
____ Hispanic
____ Asian
____ Native American
____ Other (please specify): _____
3. How many years did you complete in school? (Check highest level reached.)
____ Less than eighth grade
____ More than eighth grade, but did not graduate from high school
____ Some college
____ College graduate
____ Postgraduate
4. What is your marital status?
____ Single, never married
____ Currently married
____ Separated
____ Divorced
____ Widowed
5. If you are currently not married, do you have a significant other living with you at this time?
____ Yes
____ No

6. What are the ages of your children? (Check all that apply)
- ☐ Infant (newborn to 12 months of age)
 - ☐ Age 1 -2 years
 - ☐ Age 3 - 5 years
 - ☐ Age 6 - 12 years
 - ☐ Age 13 - 18 years
 - ☐ Age 19 - 23 years
 - ☐ Age 24 - 30
 - ☐ Older than 30 years
 - ☐ I do not have any children.
7. What is your annual household income?
- ☐ < \$10,000
 - ☐ \$10,000 - \$15,000
 - ☐ \$16,000 - \$20,000
 - ☐ \$21,000 - \$25,000
 - ☐ \$26,000 - \$30,000
 - ☐ \$31,000 - \$40,000
 - ☐ \$41,000 - \$50,000
 - ☐ \$51,000 - \$75,000
 - ☐ \$76,000 - \$100,000
 - ☐ > \$100,000
8. Are you currently employed?
- ☐ Yes
 - ☐ No
9. What year were you initially diagnosed with breast cancer?_____
- How old were you at that time?_____
10. What stage was your tumor?
- ☐ T1
 - ☐ T2
 - ☐ T3
 - ☐ T4
 - ☐ I don't know
11. Were any cancer cells found in your axillary lymph nodes with your initial surgery?
- ☐ Yes
 - ☐ No

12. What estrogen receptor status was your tumor?
____ Estrogen receptor positive
____ Estrogen receptor negative
13. What was your initial surgical treatment for breast cancer?
____ Mastectomy
____ Lumpectomy
____ Quadrectomy
____ Segmentectomy
14. What was your initial medical treatment for breast cancer?
____ Radiation only
____ Radiation and chemotherapy
____ Chemotherapy only
____ Radiation and Tamoxifen
____ Tamoxifen only
____ Radiation, chemotherapy, and Tamoxifen
____ Radiation and ovarian ablation
____ Other (please specify): _____
15. Have you had any recurrence or metastasis of cancer since your initial diagnosis of breast cancer?
____ Yes (please explain): _____
____ No
16. Who suggested your initial treatment for breast cancer? (Check all that apply)
____ Self
____ Physician
____ Spouse
____ Family member other than spouse (please explain): _____
____ Friend
____ Other (please explain): _____
17. Did you educate yourself on breast cancer? (Check all that apply)
____ Before diagnosis
____ During treatment
____ After treatment
18. Were you satisfied with your breast cancer surgical and medical treatment choices? Please explain.
____ Yes ____ No

APPENDIX B
MASSEY QUESTIONNAIRE

Massey Questionnaire

1. What information would have been most helpful to you?
(Please explain all answers)

At the time of diagnosis of breast cancer:

During treatment for breast cancer:

After treatment for breast cancer:

2. What actions, taken by yourself or others, would have been most helpful to you?

At the time of diagnosis of breast cancer:

During treatment for breast cancer:

After treatment for breast cancer:

For questions 3-11, check (✓) the answer that best applies:

3. What was your greatest need at the time of diagnosis of breast cancer?

_____ Support (from whom, please explain): _____

_____ Education concerning breast cancer, treatment, and prognosis

_____ Spiritual support, counseling or guidance

_____ Information about available surgeons and/or oncologists in your area

_____ Time with family

_____ Solitary time

_____ Other (please explain): _____

4. What was your greatest need during treatment for breast cancer?
____ Support (From whom, please explain): _____
____ Education about side effects of treatment
____ Pain relief
____ Relief measures for side effects, other than pain
____ Spiritual support, counseling or guidance
____ Time with family
____ Solitary time
____ Cosmetic (i.e., wigs, prostheses)
____ Financial support, resources
____ Relief from work or decreased work schedule
____ Relief from household upkeep responsibilities
____ Other (please explain): _____
5. What was your greatest need after treatment for breast cancer?
____ Support (From whom, please explain) _____
____ Education about signs/symptoms of cancer recurrence or metastasis
____ Financial support, resources
____ Spiritual support, counseling or guidance
____ Time with family
____ Solitary time
____ Other (please explain): _____
6. What was our greatest concern at the time of diagnosis of breast cancer?
____ Concern for own physical health
____ Concern for spouse/significant other
____ Concern for children
____ Concern about performing work responsibilities
____ Concern about finances
____ Concern about performing household responsibilities
____ Concern about treatment choices
____ Concern for spiritual self
____ Other (please explain): _____
7. Was the concern listed in #6 related to a fear of dying from cancer?
____ Yes
____ No

8. What was your greatest concern during treatment for breast cancer?
- ☐ Concern for own physical health
 - ☐ Concern for spouse/significant other
 - ☐ Concern for children
 - ☐ Concern about performing work responsibilities
 - ☐ Concern about finances
 - ☐ Concern about performing household responsibilities
 - ☐ Concern about pain
 - ☐ Concern about appropriate treatment choices
 - ☐ Concern for spiritual self
 - ☐ Concern about body image
 - ☐ Concern about side effects of treatment, other than pain
 - ☐ Other (please explain): _____
9. Was the concern listed in #8 related to a fear of dying from cancer?
- ☐ Yes
 - ☐ No
10. What was your greatest concern after treatment for breast cancer?
- ☐ Concern for own physical health
 - ☐ Concern for spouse/significant other
 - ☐ Concern for children
 - ☐ Concern about performing work responsibilities
 - ☐ Concern about finances
 - ☐ Concern about performing household responsibilities
 - ☐ Concern about pain
 - ☐ Concern about appropriate treatment choices
 - ☐ Concern for spiritual self
 - ☐ Concern about body image
 - ☐ Concern about cancer recurrence or metastasis
 - ☐ Other (please explain): _____
11. Was the concern listed in #10 related to a fear of dying from cancer?
- ☐ Yes
 - ☐ No

12. What would have brought you the most comfort? (Please explain all answers)

At the time of diagnosis of breast cancer:

During treatment for breast cancer:

After treatment for breast cancer:

APPENDIX C

APPROVAL OF MISSISSIPPI UNIVERSITY
FOR WOMEN'S COMMITTEE ON USE OF
HUMAN SUBJECTS IN EXPERIMENTATION



MISSISSIPPI
UNIVERSITY
FOR WOMEN

Admitting Men Since 1982

Office of the Vice President for Academic Affairs
Eudora Welty Hall
W-Box 1603
Columbus, MS 39701
(601) 329-7142

April 16, 1999

Ms. Lu Ann Massey
c/o Graduate Program in Nursing
Campus

Dear Ms. Massey:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research upon the condition that you keep all documents secure and under lock and key.

I wish you much success in your research.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Susan Kupisch', written over the printed name.

Susan Kupisch, Ph.D.
Vice President
for Academic Affairs

SK:wr

cc: Mr. Jim Davidson
Dr. Mary Pat Curtis
Dr. Bonnie Lockard

APPENDIX D

CONSENT OF DIRECTOR
TO CONDUCT STUDY

LuAnn S. Massey
6682 Plumlee Cove West
Memphis, TN 38141

Pat McRee, Director
Flying Colors
1068 Cresthaven Road
Memphis, TN 38119

Dear Ms. McRee,

I have spoken and met with you previously concerning my planned research study. As a graduate student at Mississippi University for Women, School of Nursing in Columbus, Mississippi, I am conducting a study entitled, "Identification of Needs in Treatment of Breast Cancer."

The purpose of this study will be to obtain and identify information regarding the needs of women with breast cancer during the various stages of treatment. I am requesting your written permission to utilize your support center clients in my research study.

Participation by the subjects will be on a voluntary basis, and subjects will be informed of the details of the study. Participant identification in this study will remain anonymous.

The information obtained in this study will identify needs, fears, and concerns of women with breast cancer during the various treatment stages; at the time of diagnosis of breast cancer, during treatment for breast cancer, and after treatment for breast cancer. The information obtained can be utilized to anticipate and address these concerns and needs, and to also enable persons associated with women with breast cancer to attempt to understand more fully what the women with breast cancer are experiencing. By anticipating these fears, concerns, or needs, information, education, and resources can be on hand to better assist the women with breast cancer concerning these issues.

I am enclosing a duplicate of this letter for your records. Please return the signed original to me in the enclosed envelope. Thank you for your consideration regarding this request.

Sincerely,

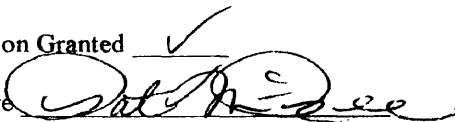


LuAnn S. Massey, R.N., B.S.N.

Permission Granted ☒

Permission Denied ☐

Signature



Date 5-19-99

APPENDIX E
INFORMED CONSENT

Informed Consent

I give my permission to LuAnn S. Massey, RN, BSN, to participate in the research study she will be conducting on women with breast cancer. I understand the questions I will be answering will be used in the research study for information and statistical purposes. The information obtained in this study will identify needs, fears, and concerns of women with breast cancer during the various treatment stages; at the time of diagnosis of breast cancer, during treatment for breast cancer, and after treatment for breast cancer. The information obtained can be utilized to anticipate and address these concerns and needs, and to also enable persons associated with women with breast cancer to attempt to understand more fully what the women with breast cancer are experiencing. By anticipating these fears, concerns, or needs, information, education, and resources can be on hand to better assist the women with breast cancer concerning these issues. I understand my identity in the study will be anonymous and that the completed questionnaires will be viewed only by the researcher, Ms. Massey. I also understand my participation in the study is voluntary.

Further information regarding this study may be received from:

LuAnn S. Massey, RN, BSN
Telephone: (901) 794-9320

I have been given a verbal description of this study and have no further questions to be answered. I grant my permission to LuAnn S. Massey, RN, BSN, to include me in her research study.

_____ Yes _____ No

Signature: _____

Date: _____

Witness: _____

Date: _____